

endure. For security reasons they will not be allowed to visit the “dead” person; they will not be able to have any physical contact with him or her. On the other hand, they will have a difficult time accepting that the person is really dead while still showing so many signs of life. Even if they do accept that he or she is dead as a person, even if not biologically dead, there will be no body to put to rest, no proper ceremony of death and no appropriate end to their relationship with him or her. And this situation may go on for years. This is not what most people can accept as a good death.

Suppose the person had agreed to be the subject of xenotransplantation experiments and that this was put in the person’s living will. Do the wishes of these people override the discomfort, inconvenience or even anguish of their relatives? In my view, they do not. As death and dying have a social meaning, as death is a process that includes the dying person’s relationships with other people and, as these relationships can be extremely important for the people concerned, the dying person is not entitled to make the decision. Individual freedom has limits in this case as in others. The wishes of the dying people should be taken into account, but it would not be wrong for a society to allow their choice to be overruled by the wishes and concerns of those who are closely related to them. In fact, there is a stronger argument for giving decisive weight to the wishes of relatives in this case than in cases where brain-dead people are used as the source of organs for transplantation. Harvesting organs from brain-dead people does not so seriously disrupt the relationship of the living with the dying or the dead.

Does the prospect of being able to save many more lives by means of xenotransplantation give us good reason to override the wishes of relatives (or, for that matter, the wishes of dying people themselves)? Obviously, the answer is no. The prolongation of life at the expense of relationships that give meaning and dignity to life and to death is not morally acceptable. A society should not go down that road.

Nevertheless, these concerns are not reasons for prohibiting xenotransplantation experiments. Some relatives of people who are in a permanent vegetative state may be willing to allow their loved ones to be used in this way, especially if they believe that the person wanted this to happen and if they are persuaded of the importance of the experiment. Consent in this case, however, ought to be a collective commitment. Ideally, people who would want their bodies to be used for such experiments if they were to remain in a permanent vegetative state ought to seek the consent of the people with whom they have a close relationship, and these people ought to be fully informed about the consequences of consenting. There could be a formal process of obtaining joint consent from relatives and spouses with appropriate counselling. Alternatively, close relatives could be asked for their consent after a person who has already consented to be subjected to the experiment has lapsed into a permanent vegetative state. If, however, they are unprepared and know little or nothing about what their loved one had consented to, they may be extremely distressed by the idea or may not understand what is being asked of them. Consent would be more meaningful if the people directly affected were able to make a decision in advance—expressing and taking

into account what they regard as a good death.

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References

- 1 Lock M. *Twice dead: organ transplants and the reinvention of death*. Berkeley, LA: University of California Press, 2002:130–48.
- 2 Ravelingien A, Mortier F, Mortier E, et al. Proceeding with clinical trials of animal to human organ transplantation: a way out of the dilemma. *J Med Ethics* 2004;30:92–8.

Respecting rights ... to death

Ravelingien *et al*¹ argue that, given the restrictions that must be imposed on recipients of xenotransplanted organs, we should conduct clinical trials of xenotransplantation only on patients in a persistent vegetative state. I argue that there is no ethical barrier to using terminally ill patients instead. Such patients can choose to waive their rights to the liberties that xenotransplantation would probably restrict; it is surely rational to prefer to waive your rights rather than to die, and permissible to allow patients to make this choice.

Perhaps the single most important advance in the history of moral thought occurred when it came to be generally recognised that all people are protected by rights that are inviolable, at least without their consent. The precise nature and content of these rights is controversial, but there is a consensus among reasonable people over their core. We all have a right to life, to liberty, to security of person and to equality before the law. Other rights—so-called positive rights, such as the right to economic security, or cultural rights, for instance—may be controversial, but we all agree at least on these.

Ravelingien *et al*¹ therefore seem to be on solid ground when they conclude that it would not be permissible to use living persons as subjects in clinical trials of xenotransplantation, as such trials, potentially or actually, result in the violation of the core human rights of the subjects. Their argument is as follows:

Xenotransplantation carries with it a currently unquantifiable risk of the transmission of viruses, from the animal that is the source of the organ transplanted, to the human recipient. Such viruses could have potentially catastrophic consequences, up to and including triggering a global and devastating pandemic. Therefore, it would be necessary to monitor the health status of recipients of donated organs for many years, even decades, to ensure that the symptoms of such infections have not developed. Xenotransplant recipients would therefore need to submit to a regime of intensive and extensive scrutiny. They would have to make

themselves available for regular testing and their sexual partners would have to be warned of the potential for infection. They might be advised to forgo having children. Worst of all, if signs of an infection are detected, or if the risks are felt to be great enough, they might find themselves confined in quarantine. But all of these actions are violations of their human rights. Since we have a right to shape our life as we see fit, to associate with whom we like and to travel where we like, we cannot morally be treated in the ways that xenotransplantation to persons would necessitate.

Ravelingien *et al*¹ therefore suggest that, xenotransplantation trials should be conducted only on people who are in a persistent vegetative state. As such people no longer have an interest in freedom of movement and association, we do not violate their rights by confining them. If they had, when competent, consented to participate in such trials, using their bodies for clinical trials of xenotransplantation should be no more controversial than the range of uses to which we currently put cadavers in research and in training surgeons.

This proposal, however, faces a serious objection. If it is permissible to use patients in a permanent vegetative state (PVS) for clinical trials of xenotransplantation (and I think it is, if all safety considerations can be successfully dealt with), then why is it not permissible to give such transplants to patients who would otherwise die? The use of terminally ill patients, rather than patients in a PVS, has several advantages.

Firstly, any virus transmitted from animal donors to human recipients might possibly produce effects in normal people, but none in patients in a PVS. This would be the case, most obviously, if the virus attacked those parts of the brain that are irretrievably damaged in patients in a PVS, such as the cortices, while leaving the brain stem unaffected. To that extent, a competent agent would be a better subject for clinical trials than a patient in a PVS.

Secondly, terminally ill patients could potentially benefit from xenotransplantation, by receiving a more or less lengthy extension of their lives as a result of participation in the trial. For the same reasons that patients in a PVS cannot be harmed by the restrictions the trials would require, they cannot be benefited either. Conversely, for the same reasons that the terminally ill can (potentially) be harmed by these restrictions, they can be benefited.

Ravelingien *et al*¹ argue that we cannot ethically place such restrictions on people who have done nothing to deserve them. This seems false to me. Although we are prohibited from violating the rights of others, anyone is entitled to waive their own rights. Indeed, if our rights survive the loss of consciousness, as they surely do, then Ravelingien *et al*¹ must concede that this is so: patients in a PVS may only be used as subjects in xenotransplantation experiments with their prior consent, they argue; in other words, when they have waived their rights to certain kinds of treatment when they are no longer competent. In the absence of this

waiver, patients in a PVS plausibly have their rights violated, even if they are not harmed by the procedure. But if one class of patients can waive their rights, they why not the other, especially when only the second class of patients can benefit from the experimentation to which they consent?

If patients can avoid death only at the cost of sacrificing some or all of their rights to freedom of movement or association, then they have a right to make this choice, and, assuming that no one is responsible for the predicament that forces them to choose between these options, no one has acted unethically. To see this, consider the absurd consequences of implementing the proposal advocated by Ravelingien *et al.*¹ A patient with a terminal illness may volunteer to participate in potentially life-saving xenotransplantation clinical trials. The scientists conducting these trials would be forced to respond: "We cannot use you now; make a living will and perhaps we shall consider you once you die." The patients are assured that their rights will be respected, but this is small comfort.

Of course, as Ravelingien *et al.*¹ point out, patients who consent to the restrictions envisaged as a condition of participating in clinical trials may change their minds after receiving the transplant. We should have to be prepared to continue to restrict their movement, even against their wishes. I do not see this as a great worry. If there is a real and definite public health risk, then we would have to be prepared to restrict their movement in any case, whether or not they had consented to participate in the trials. We already possess the right, and the responsibility, to protect public health, even at the cost of infringing on another's rights: carriers of infectious diseases can already be quarantined against their wishes. The fact that recipients had agreed to participate in the trials simply makes our decision easier. Therefore, no ethical barrier prevents the use of terminally ill patients in xenotransplantation trials.

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Reference

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Authors' reply: A body at will

We thank Robert Sparrow¹, Steven Curry¹, Heather Draper³, Janna Thompson⁴ and Neil Levy⁵ for their contributions in discussing the difficulties and possible implications of our defence of willed body donation for xenotransplantation (and, plausibly, other types of) research on bodies in a permanent vegetative state (PVS). We will deal with four crucial objections raised in their commentaries.

Firstly, there is hesitancy about the claim that the PVS can be regarded as death. Secondly, the moral weight of the prior consent of "the deceased" is questioned in the light of conflicting interests of the living. Thirdly, the opinion is held that our utilitarian motivation to conduct the research

cannot but defend an ultrautilitarian denial of the importance of prior consent. Finally, it is thought to be preferable to argue for the use of terminally ill patients rather than bodies in a PVS.

Our reply rests on the assumption that the requirements we listed in the original formulation of our suggestion—certain diagnosis of the irreversibility of the state; sufficient and relevant functioning of a body in a PVS to obtain useful results; and prior informed consent⁶—can be maintained along with an additional condition pointed out by one of the commentators that a sufficient number of consenting adults can be obtained in advance.

Firstly, the objection is raised that the PVS either cannot or should not be regarded as death. We are said to believe that "PVS patients are in fact dead". The commentators hold this seemingly straightforward and objective claim to be either factually untrue—an assumption that leads several authors to argue that we are dealing with living patients, "albeit with a very poor quality of life"—or logically inconsistent with the way in which we leave room for subjective judgement.

In response to the question of whether patients in a PVS are in fact dead, we want to make the following remarks. Speaking of a "patient" in a PVS (let alone, of a "person" in a PVS, an equally unfortunate choice of words used in some of the commentaries) is a contradiction in terms and impedes the discussion. We argued that the word "patient" is inappropriate in relation to the condition because it generally refers to a living person, whereas the bodies we conceive of are permanently devoid of all forms of personhood, even of the minimum requirement for the capacity of personhood, although the body is still biologically active. Given that the person no longer exists, it makes sense only to speak of—indeed, living—bodies in a PVS.

That the person is dead whereas the body remains alive is the essential requirement of our proposal. It is neither a matter of opinion nor a matter of ethics. That a demonstrably irreversible vegetative state implies that the person has died leaving behind a living human body is a fact that is in keeping with the specialisation of the brain (eg, cerebral cortex *v* brainstem function). The question that remains, however, is of what value can be attributed to such a living, person-void body. It is only with regard to this question that we leave room for subjective judgement.

The fact that the person in a demonstrable and irreversible PVS is dead explains why we cannot accept the alternatives offered by both Curry² and Draper³. According to Curry, provided that prior informed consent is sought, "living PVS patients" may be enrolled in xenotransplantation experiments—just as healthy subjects may enrol for phase I and II drug trials—because they are "in exactly the right kinds of ways" not like other patients:

It just so happens that PVS patients do not have any of the interests listed by the authors. Persons who are in a PVS will never wake up, they feel no pain or discomfort, and have no continuing interest in their own survival. Even if one thinks that PVS patients have a right to life (on

*even the most contentious meaning of this term), these patients must also have a right to risk that life for the common good. [the italics are ours]*²

Similarly, Draper argues that if a person in a PVS wishes to participate in xenotransplantation research, this is a matter of life-style choices, a matter for him or her alone.³ Curry explicitly claims that this move bypasses the need to agree on whether they are dead while maintaining the motivation to use bodies in a PVS. In effect, however, such claims miss the point. They presuppose personhood and as such fail to strengthen our argument. A person in a PVS cannot decide to risk his or her life for the common good, for there no longer is a person who can consider taking a risk. He or she can only decide in advance (t1), and to a certain extent, the fate of his or her body once he or she, as a person, ceases to exist (t2).

The decision of what may happen to the body at t2 is dependent on the importance attached to the death of the person at t1. Various scenarios of how to dispose off the bodily (living) remains, comparable to scenarios of how to dispose off the corpse, are conceivable in relation to the prior sensed value of the person-void body. These include the decision to keep the body alive or to allow it to die. In the case in which the body is allowed to die, it becomes a cadaver and wishes about retention of non-living bodily remains become applicable. In the case in which the body is to be kept alive, we can choose to either have it left untouched or—the option that we open up—donate it for research purposes.

Whether the person is dead or alive is not, or should not be, contestable. Whether the death of the person (or, alternatively, his or her existence) is what matters in valuing life, however, is contestable. This question of determining what it is to be dead (or non-existent) lies at the definition or concept level. This fundamental level is subject to philosophical and theological beliefs, whereas the other more objective levels—the levels regarding the criteria and medical diagnostics—are essentially a matter of natural sciences.⁷ Disagreement at each of the three levels remains, but that at the level of definition has the greatest effect, which explains why people may hold different opinions on what it means for a human being to be dead.

That there can be very different ways of understanding among people does not mean that there are no limits to which concepts of death can be applied. If that were the case, we would need to accept an endless possibility of alternative definitions of death, as one commentator points out. It is, however, reasonable to claim that the death of the person is a sufficient condition for what it means to be dead. This is because of the common ground with the current concept of brainstem death. It is the irreversible loss of consciousness and thus of any capacity for personhood rather than the loss of brainstem functioning that lies at the base of accepting whole brainstem death. The death of the person is a necessary condition for meeting certain wishes regarding treatment of the body, and this is, by definition, the case for both whole brain death and cortical brainstem death.